

questionnaires in e.g. gay magazines, so the sample of MSM has not been well defined. Also, the latest studies are from around 1990, but they have all shown a decreasing number of sexual partners during the 1980's and an increasing use of condoms. However, they have not found a decreasing trend in the proportion of MSM who practise insertive anal sex. Most of the data has been published as part of a EU-study or in a PhD-thesis.

A cross-sectional study using a questionnaire given to all known HIV-infected women in Denmark was done in 1994, including questions on self-reported change in sexual behaviour after realising the women were HIV-infected. The main results were that most women experienced great problems when realizing they were HIV infected. Most stopped having sex for a long while and reported being depressed and feeling "dirty" as women. Data has partly been published in a PhD-thesis.

HIV/AIDS PROGRAM EFFECTIVENESS MONITORED AND EVALUATED BY SURVEILLANCES OR SURVEYS

Although the HIV prevention strategy and the focus of the information campaigns are the responsibility of the National Board of Health, there has been a political acceptance of the principles for the HIV/AIDS prevention initiatives for the last 10 years. This was declared by the parliament in 1987 and recently - after a long debate in the parliament - reconfirmed by a great political majority. The principles are: That no one can be tested against his will and the right of all individuals to be HIV tested anonymously and free of charge. Also, the information given by health authorities must be open, direct and honest, and any kind of discrimination must be avoided. The parliament allocates about 5 million US dollars per year for the HIV/AIDS-preventive activities. The National Board of Health gets about 2 million US dollars to undertake information, education, prevention and evaluation activities. Also, the parliament donates money to NGOs such as the existing national umbrella-organisation for HIV-infected people and the Gay and Lesbian Organisation.

Really good evaluation of the national campaigns has not been undertaken, but indirect measures have been used, such as the massive decrease of the incidence of gonorrhoea. This has been seen as an indication of widely use of condoms in the populations at risk. However, as shown, this decrease had already started when the campaigns were introduced and did not change a lot after the abolishment of the Venereal Disease Act.

Due to the great impact on the natural history of HIV of the new antiretroviral combination therapies the AIDS surveillance has lost most of its importance as a tool to follow the HIV incidence and prevalence. Therefore, we are now working on a revision of the HIV surveillance system in order to be able to use named reporting of new HIV-infected cases. This might be political acceptable now – but has not been so in the past. The main obstacle will be the political discussion on the right of anonymity, which has been politically stated several times. The need of other ways to monitor/estimate the HIV incidence and/or HIV prevalence in our populations are obvious, since e.g. the back-calculation methods based on AIDS data now may be of limited use.

The results from the HIV-surveillance system have had a strong influence on the chosen national information campaigns. The National Board of Health has every second year interviewed a random sample of Danes on their knowledge of HIV/AIDS, risks, mode of transmission etc., as well as their attitudes. Data on behaviour has not been included. These data has shown that Danes are very well informed about HIV and are fairly realistic in the way they deal with the problem.

In 1998 the National Board of Health asked a professional company to evaluate the HIV/AIDS-prevention strategy and campaigns done in 1990-96. The report concluded that the strategy used was a “crises management”, but that it was time for a change. This has now resulted in a re-thinking of the strategy, mainly focusing on including information and education on STDs and unwanted pregnancies in the HIV-prevention activities. Also, the general campaigns meant for the wider population will be reduced and instead focus will be put on the 6 identified core-groups:

- MSM
- IDUs
- Certain groups of Danes travelling abroad
- Ethnic minorities
- HIV-infected people
- the adolescents/young adults (15-24 years of age).

CONCLUSION

The spread of HIV is limited in Denmark, although the overall prevalence in the population is around 0.1% and increasing these years due to the effect of antiretroviral therapy.

The challenge for the years to come are to revise the surveillance systems in order to be able to

make reliable estimates of the HIV incidence.

Due to the impact on AIDS incidence and mortality of the new antiretroviral treatment regimes, implementations of national HIV-surveillance systems are strongly recommended. AIDS-surveillance systems already in place should be kept until time has shown if the impact of treatment is long-term. The need of good ways to estimate HIV incidence and/or HIV prevalence in our populations are obviously needed, since e.g. the back-calculation methods based on AIDS data now may be of limited use.

The Danish mandatory and anonymous HIV-surveillance system has shown to be very useful in such a small country like mine, but has its limitations. We are now working on a revision of the system in order to be able to use named reporting of new HIV-infected cases. This might be political acceptable now – but has not been so in the past, as far as I can see. The results from the HIV-surveillance system have had a strong influence on the chosen national campaigns.

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HIV/AIDS Surveillance Country Report Germany

Osamah Hamouda MD, MPH

1. Introduction

When word of the AIDS epidemic reached Germany, it was far from being well prepared to meet the challenges posed by a new infectious disease. In the era of antibiotics, infectious diseases - as in many other countries - were not a major concern of public health policy. This changed very quickly as the number of AIDS cases reported to the „AIDS task group“ at the Robert Koch Institute (RKI, Federal Institute subordinate to the Ministry of Health) continued to increase. The Ministry of Health founded a national AIDS Centre which concentrated expertise in the fields of epidemiology, virology, clinical and psychosocial research programs as well as prevention. Within a few years the AIDS Centre developed into a strong unit as part of the Federal Health Office. In the course of time, the AIDS Centre developed into a group that was the starting point of rebuilding an effective Infectious Disease Epidemiology branch at the RKI. After some organizational changes The AIDS Centre is now part of the Department of Epidemiology and Health Reporting at the RKI.

2. HIV/AIDS-related surveillance and surveys

2.1 AIDS case surveillance

2.1.1 Organizational and legal structures for surveillance

Since 1982 - the year that the first AIDS case was reported in Germany - information on AIDS cases is collected at the national register in the AIDS-Centre of the Robert Koch Institute. There is no mandatory reporting of AIDS cases or deaths in Germany. Reports on standardized questionnaires are made on a voluntary basis by the clinicians and private practice doctors treating the patients.

2.1.2 Reporting system

AIDS case reports are sent by doctors directly to the Robert Koch Institute. The reports contain reliable information on sex, year of birth, region of residence, transmission route, AIDS defining diseases, date of diagnosis and antiretroviral treatment prior to AIDS diagnosis. In order to detect duplicate reports, a code consisting of the third letter of the name and the number of letters in the name both for first and last name is used as a unique identifier in combination with year of birth and sex. After data entry, the codes are kept in a separate file and only the data set without the codes is used for further analysis.

2.1.3 AIDS case definition and validation

The AIDS definition used for surveillance of AIDS cases throughout the European countries collaborating with the European Centre for the Epidemiological Monitoring of AIDS in St.Maurice, France is used in Germany. Incoming case reports are checked for consistency and agreement with the case definition.

2.1.4 Results of AIDS case surveillance

The first cases of AIDS in Germany were reported in 1982. Within only a few years the AIDS incidence reached 1600 per year in 1989 and continued to increase less rapidly until it reached a peak of about 2000 cases per year in 1993. In 1993/94 the AIDS incidence leveled off. As in many North American and European countries, AIDS incidence began to decline in 1995 following the widespread use of highly effective antiretroviral treatment. After steep declines of AIDS incidence in 1996 and 1997 to about 900 cases per year, the latest data indicate that the decline of AIDS incidence has come to an end in 1998. It is still too early to say whether the expected increase of AIDS incidence due to therapy failure is beginning to occur.

A total of 17955 AIDS cases were reported in Germany until the end of 1998. Almost two thirds (65%) of all reported cases are men who have sex with men (MSM). Intravenous drugusers (IDU) are the second largest group and make up about 15% of all AIDS cases, followed by 6% of persons infected through heterosexual contact (HETERO). Mostly due to the influence of therapy, the proportion of homo-/bisexual men who develop AIDS has decreased substantially over the last few years. Among persons diagnosed with AIDS in 1998 only 48% were MSM, while IDU, HETERO and people originating from high prevalence countries (pattern-II countries) each made up 11%. The proportion of AIDS cases with an unknown/unstated mode of transmission has increased to 18% in 1998.

The AIDS epidemic in Germany is clustered in and around the metropolitan areas. More than half of all AIDS cases are from six cities: Berlin, Frankfurt a. Main, Munich, Hamburg, Dusseldorf and Cologne.

2.1.5 Dissemination and actions which result

Quarterly reports containing a number of tables and figures on the latest results on both the HIV and AIDS reporting systems are sent out to the federal and state health ministries, to the local health offices of bigger cities (pop. > 100.000), to a number of research institutes and universities as well as all doctors who contributed reports. A yearly report which contains a more detailed analysis of the whole HIV/AIDS epidemic up to the end of the year is also prepared. Both publications are sent out free of charge. Abstracts of the latest results and colour slides are available on the internet.

2.1.6 Problems and future perspectives

In the time of declining AIDS incidence it is becoming more difficult to convey to politicians as well as some public health officials, that AIDS case surveillance remains an indispensable tool in monitoring the HIV/AIDS epidemic. It is therefore becoming more difficult to secure the funds that are necessary to maintain the high quality of AIDS case surveillance that has been established over the past years.

2.2 HIV case surveillance

2.2.1 Organizational and legal structures for surveillance

In October 1987, the Mandatory Laboratory Reporting Ordinance came into effect. All laboratories performing HIV confirmatory testing are required to report positive results anonymously to the AIDS-Centre at the Robert Koch Institute. No personal identifiers are collected in order to ensure complete anonymity and to underline the prevention policy goal of encouraging voluntary testing. Before 1987 the Deutsche Vereinigung zur Bekämpfung der Viruskrankheiten (DVV -German Association for the Control of Viral Diseases) in collaboration with the Federal Health Office conducted a voluntary reporting system for HIV infections.

2.2.2 Reporting system

HIV is reported directly to the Robert Koch Institute, whereas all other reportable diseases are first reported to the local health department and then forwarded to the state and then the national level. Reporting is completely anonymous. Until June 1998 no unique identifier or any other form of code was used.

The law governing the reporting of infectious diseases is currently being revised. The new law will introduce the same unique identifier used in the AIDS case registry for HIV case reporting and will also provide for additional information to be collected from the treating physician. Currently the new reporting system is run on a voluntary basis since July 1998.

2.2.3 HIV case definition and validation

There is no specific HIV case definition issued by the RKI. Guidelines for laboratories are made by the DVV based on WHO recommendations. In more than 95% of the reported HIV infections, Western blot is used as confirmatory test. Completeness of reporting is estimated to exceed 95%. The detection of duplicates poses a substantial problem, since a unique identifier was only recently introduced to the system. Until 1992, only cases whose report indicated „known to have been previously tested HIV positive“ were counted as duplicates, those who had an unknown history of previous testing were not counted as duplicates. In 1993, the coding of the question was changed and since then, only those reports are considered to be from „first time testers“ where the report explicitly states „not previously tested HIV positive before“. Since July 1998, about half of the reports coming in have the unique identifier.

2.2.4 Results of HIV case surveillance

The number of newly diagnosed HIV infections in Germany has remained fairly stable at around 2000 to 2500 per year since 1993. There has been a moderate decline in the number of diagnosed HIV infections from 1993 to 1996 and a slight increase was observed in the last two years. This increase is most probably due to increased testing because of improved treatment rather than a reflection of an increase of new HIV infections.

Among those reported as newly diagnosed HIV infections in 1998, the largest proportion (40%) were MSM. The proportion of HETERO and PATTERN-II were 16% each while IDU made up 10% of newly diagnosed HIV infections. The proportion of diagnosed infections with no risk identified was 17%. The regional distribution of HIV-infections is almost identical to the distribution of AIDS cases (see 2.1.4).

2.2.5 Dissemination and actions which result

see 2.1.5

2.2.6 Problems and future perspectives

Clearly the biggest problem of the HIV reporting system was that it lacked a unique identifier. This problem is being tackled and hopefully will be solved with the passing of the new Infectious Diseases Law. Also, reporting of transmission group category has improved over the last few years and is expected to further improve as collecting data directly from the treating physician is facilitated in the future.

2.3 Sentinel sero-surveillance

2.3.1 Organizational and legal structures for surveillance

A small program of sentinel sero-surveillance is carried out by the Robert Koch Institute on a regular basis since 1993. The procedure used in the unlinked anonymous testing has been approved by state and federal officials responsible for data confidentiality, but there is no specific legal regulation concerning sentinel sero-surveillance. The main aim of the program is to estimate the prevalence of HIV infection among childbearing women as a marker of seroprevalence in the general population.

2.3.2 Sampled population and sampling procedures

Unlinked anonymous testing of dried blood spots from newborns is carried out in two federal states: one metropolitan state (Berlin) and one mainly rural state (Niedersachsen). Samples from all newborns in each of these two federal states are collected in one central laboratory and tested for HIV antibodies. A total of about 30000 samples in Berlin and about 75000 samples in Niedersachsen are tested every year. Coverage includes over 95% of all newborns in these two states.

2.3.3 Measurements

Unlinked anonymous testing is performed by taking a 5mm diameter sample from Guthrie cards used for screening. Pools of six samples are screened with a commercial ELISA test kit. Samples from reactive pools are tested separately and confirmed by Western blot. No other items other than HIV antibodies are routinely measured.

2.3.4 Reporting system

Test results from each of the two laboratories are reported to the RKI on a monthly basis. Data collected other than serostatus are only month of birth and region of residence (first three digits of the five digit postal code). It is not possible (and not intended) to trace a positive result back to a certain individual.

2.3.5 Results of sentinel sero-surveillance

The average rate of HIV seropositives in the time period 1993 to 1997 among mothers who give birth is 0.57 per 1000 in Berlin and 0.14 per 1000 in Niedersachsen. These rates have been stable over the whole time period since testing began.

2.3.6 Dissemination and actions which result

The results of the unlinked anonymous testing program have been published at international meetings and are also published by the AIDS Centre in the yearly report (see 2.1.5).

2.3.7 Problems and future perspectives

As of end 1998 the program is financed as a research program by the Ministry of Health on a year-by-year basis. This makes long term planning difficult. Funds for sentinel sero-surveillance should be transferred to the disposition of the RKI in the near future. The samples (or a subsample) could be used to simultaneously test for other infectious agents of public health interest.

2.4 Behavioural surveillance

2.4.1 Organizational and legal structures for surveillance

Health promotion in general and the planning and implementation of the nationwide AIDS prevention programs addressed to the general public are tasks of the Federal Centre for Health Education (BZgA, Bundeszentrale für gesundheitliche Aufklärung), a special unit within the sphere of responsibility of the Federal Ministry of Health. Surveillance of behaviour and attitudes in the general public are carried out by the BZgA since 1987. The planning and implementation of nationwide prevention campaigns for high risk groups is done primarily by non governmental, non-profit organizations such as the Deutsche AIDS-Hilfe (German Association of AIDS Self-help Groups).

2.4.2 Sampled population and sampling procedures

A representative sample of 2000 participants from the general population aged 16 years or older are questioned by computer aided telephone interview using a standardized questionnaire. The sample covers all of Germany (including former East Germany since 1991). The survey is repeated at yearly intervals.

Surveys in high risk groups are done primarily as research projects at the local level in irregular intervals.

2.4.3 Measurements

The survey covers 100 items including acceptance levels of the different media used in the prevention program as well as personal knowledge, attitudes and behaviour.

2.4.4 Reporting system

The results of the survey are published in a report and fed back directly to the prevention program.

2.4.5 Results of behavioural surveillance

TV spots and newspaper ads remain the primary source of information concerning AIDS for the general public. More than 90% of the population is reached by the program. There is a high level of information concerning general knowledge about the disease and of risk factors for transmission. Knowledge about the correct use of condoms has increased in recent years, especially among young women. Acceptance and use of

condoms has increased over the years especially among the younger age groups and persons with more than one sex partner.

2.4.6 Dissemination and actions which result

As the results of the survey are fed back directly to the prevention program, it can be modified at short notice according to the requirements.

2.4.7 Problems and future perspectives

A large proportion of the resources available are spent on information campaigns directed at the general public who are currently at a low risk of acquiring an HIV infection. Groups with a high risk of infection should receive a greater degree of attention in the future.

3 HIV/AIDS Program effectiveness monitored and evaluated by surveillances or surveys

Surveillance and survey data from the different systems show that the HIV/AIDS epidemic in Germany has been kept at a low level when compared to most other European countries. This is in part due to the fact that the non governmental organisations were supported by the German government at an early phase of the epidemic in order to direct specific prevention programs to the groups at highest risk for infection. This timely intervention was complemented with the implementation of a massive nationwide AIDS prevention program addressed to the general public. The national surveillance systems play an indispensable role in the monitoring of the HIV/AIDS epidemic and identifying primary target groups for current and future intervention programs.

4 Conclusion

Although Germany was not very well prepared to face the challenge of a newly emerging epidemic, it has managed to react quickly and adequately. HIV incidence and prevalence have remained at a low level compared to many European countries. Part of this success can be attributed to the effective HIV/AIDS surveillance system established. But as AIDS is more and more becoming a treatable disease in the eyes of many, it is becoming increasingly difficult to convince politicians to supply the necessary funds to maintain the current standard of HIV/AIDS surveillance in Germany

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1. INTRODUCTION

The UK has had well developed surveillance since very early in the HIV epidemic but, with the changes consequent on the advances in treatment and the decreasing incidence of AIDS and increasing prevalence of HIV and enormously rapid reduction in mortality over the last two years, surveillance is having to adjust.

The Public Health Laboratory Service Communicable Disease Surveillance Centre (hereafter referred to as CDSC) is responsible for the surveillance of HIV/AIDS within the UK and collaborates closely with the following organisations in pulling together the United Kingdom data:

- a) The Scottish Centre for Infection and Environmental Health (SCIEH) which undertakes surveillance in Scotland and which contributes data to the UK dataset.
- b) The Institute of Child Health (ICH) which undertakes surveillance on paediatric acquired infections and which contributes data to the UK dataset.
- c) The UK Haemophilia Centre Directors' Organisation (UK-haem) - The Oxford Haemophilia Centre co-ordinates data on haemophilia within the UK and undertakes with CDSC surveillance of HIV in haemophiliacs.

In addition, close collaboration is maintained with clinical centres seeing large numbers of HIV/AIDS patients, with HIV prevention organisations making use of the data and with the Department of Health where a national policy is implemented, the epidemiology playing an important role.

2. HIV/AIDS RELATED SURVEILLANCE OR SURVEYS

(1) AIDS case surveillance

The Communicable Disease Surveillance Centre (CDSC) is responsible for AIDS case surveillance together with the institutions mentioned above (i.e. SCIEH, ICH and UK Haemophilia Centre Directors' Organisation). Cases were asked to be reported from an appeal in the Communicable Disease Report in the summer of 1982 and small numbers were reported in the years from 1982 to 1985. At the end of 1984 when HIV testing came into widespread use in major centres in London and throughout the country in early 1985, an appeal for microbiology departments to report newly diagnosed HIV infection was also made. AIDS case reporting was never a statutory legal requirement and the context within the UK is not of statutory notification of AIDS cases but a voluntary confidential system.

i) Reporting system

Most (about two thirds) of AIDS case reports come from the London region from a wide variety of clinicians who directly care for HIV related clinical illness. Attached is a copy of our current surveillance form which has undergone major revisions over time but basically includes demographic items. (Soundex code, date of birth and sex for

identification of duplicates and linking with HIV infection reports), exposure category information, ethnicity, whether the person was born outside the UK, AIDS defining illness and date at which the first AIDS defining illness diagnosis was made, date of HIV infection diagnosis, treatment information and date of death if the patient has already died. AIDS case reports are intended to be made as soon as possible after the AIDS diagnosis has been made but, in practice, there is a moderate reporting delay for some of the cases.

ii) AIDS case definition validation

We rely on clinicians to apply the appropriate case definitions but give telephone advice in terms of difficult cases. Duplicates are identified by having the same soundex code, date of birth and sex and if there is any query whether the person is a duplicate of an earlier reported case, we would contact the clinician who would send us both the first and second case reports.

iii) Results of case surveillance

The description of trends of cases are regularly published in the Communicable Disease Report, copies of which are attached, as well as a more comprehensive set of tables which, although not officially published, are widely distributed within the UK. Copies of both these are sent to the Expert Advisory Group on AIDS, the Department of Health and the major HIV prevention organisations as well as to local public health individuals involved in local public health action.

iv) Problems and future perspectives

With the current improvement in treatment consequent on triple therapies, AIDS is a less useful marker of progression to later stage disease, although it is clearly important to maintain surveillance for those failing treatment, for those for whatever reason may not be offered treatment, for those who refuse treatment, and lastly for those who are HIV diagnosed in their first AIDS defining illness. However treatment has fundamentally altered the progression of HIV disease to AIDS in a way that it has not done so previously. This has implications for modelling in terms of back-calculation and of working out HIV incidence from the back-calculation model.

(2) HIV case surveillance

CDSC is the responsible organisation co-ordinating the HIV dataset. Reporting from laboratories began at the end of 1984 and has continued since. A copy of a current report form is attached, although we are examining enhancements to this system to collect more behavioural data at the time of HIV diagnosis from the clinicians caring for the patient. CDSC combines data from the Scottish Centre for Infection and Environmental Health and the Institute of Child Health for the Scottish and paediatric cases, respectively. There are no statutory legal requirements for HIV case reporting in the UK, it is part of a voluntary confidential system.

i) Reporting system

All laboratories diagnosing HIV infection are asked to report to CDSC. Identifiers asked for are soundex, date of birth and sex and, in addition, exposure category, clinical details and why the patient was tested. If identifiers and exposure category are missing, the laboratory is contacted and, if necessary, the clinician caring for the patient would be contacted to obtain this information. Major centres, including the London centres, report once every three months electronically but many laboratories diagnosing smaller numbers of HIV positive patients would report via paper records when they diagnose a positive result.

ii) HIV case definition and validation

If there is any doubt about the confirmation of the seropositivity of the HIV specimen, the specimen would be sent to a reference centre. However it is generally UK policy to ask for a second specimen in case there has been any administrative hitch or mix-up of specimens. A person would only be definitely told they are HIV positive on the basis of a second specimen usually confirmed by different ELISA tests.

Duplicates are detected by soundex code and date of birth and sex. Reporting is believed to be about 80% complete. Results of case surveillance, description of trends analysis of reports are regularly put in the Communicable Disease Report and our Quarterly Surveillance tables. They are also now available on the CDSC web site. Dissemination and actions which result are the same as given above in AIDS case surveillance.

iii) Problems and future perspectives

Since 1990 we have had two thousand five hundred new HIV infections diagnosed each year. One of the major difficulties currently is whether to seek further detailed behavioural information (including last negative tests) of HIV infection risk especially for gay men (most current transmission is occurring in this risk group).

(3) Sentinel sero-surveillance

i) Organisational legal structures for surveillance

Responsible organisations are CDSC for England, Wales and N. Ireland and SCIEH for Scotland. Unlinked anonymous programmes from sentinel sero-surveillance specimens began in 1990 after widespread discussion around the ethics and legal requirements in 1988 and 1989 (copy of the BMJ article plus CDR article attached).

ii) Sampled populations and sampling procedures

Sampled populations include genitourinary medicine (STD) clinics using syphilis serology - 7 centres in London and 8 elsewhere. Specimen numbers in 1997 were over 70,000 tested and the cumulative number of specimens tested from 1990 to 1997 was over 400,000.

A salivary voluntary survey covers 8 centres in London, 30 centres elsewhere. Specimen numbers in 1997 2,700, cumulative 22,000 1990-1997.

From hospital blood counts in 7 London centres there were 63,000 specimens in 1997 cumulative 420,000 (this survey is now discontinued).

Pregnant women from the infant dried blood spot surveyed 29 centres in London 92 elsewhere - the number of specimens in 1997 was 420,000 and the cumulative 1990-1997 was 2,500,000. Antenatal rubella serology 15 London centres, 88,000 specimens in 1997, 800,000 cumulative 1990-7.

Pregnancy terminations - blood grouping specimens, 8 centres in London and 7,300 specimens in 1997 cumulative 45,000.

Sampling methods are continuous surveys apart from injecting drug users where new centres are recruited as existing centres sometimes opt out of the programme. The STD clinic attendance uses syphilis serology but repeat syphilis serology done within the three month period is not re-tested. Laboratory tests utilise pooling of specimens to keep costs as low as possible.

iii) Reporting system

The specimens have all patient identifying details permanently removed before testing. Individual test results can therefore never be traced back or linked in any way to the source patient, thus specimens are tested, not people. However some data items including age range, sex, ethnicity and sexual orientation, and whether the person is already known to be HIV positive, are included on the data items which are linked. The results of sentinel sero surveillance with a description of the trends up to and including 1997 is given in the Unlinked Anonymous Report, a copy of which is attached, (both the short summary report and the main report). In brief this shows trends in prevalence of HIV infection amongst pregnant women levelling off in the period from 1993 to 1997, both in inner and outer London, the prevalence being much lower in the rest of England. The sero-prevalence of gay men attending STD clinics has fallen, especially in London, over the period of the unlinked anonymous programme but this is thought partly to do with those who are already known to be HIV positive being seen at specific clinics where routine syphilis serology is not performed.

iv) Results of sentinel sero-surveillance

Trends etc are described in the 1997 report attached to this documentation.

v) Dissemination and actions which result

The Unlinked Anonymous programme has played an important role in maintaining the public profile of the public health importance of HIV/AIDS within the UK, in particular the extremely low diagnosis of HIV infection in pregnant women especially in London and the need for a national campaign to highlight the importance of districts offering HIV testing to pregnant women in higher prevalence areas.

vi) Problems and future perspectives

It is going to be difficult in future to maintain the ongoing inputs on the unlinked anonymous programme in an age in which there is going to be increasingly tight resources especially as the treatment and care is consuming an increasing proportion of the budget.

4) Behavioural surveillance

A major behavioural survey, results of which have been widely disseminated within the UK, was conducted in 1990/91. This was a national survey of sexual attitudes and life styles and a repeat survey is planned for next year, funding having recently been agreed by the Government. The survey was well structured and almost 19,000 interviews conducted.

Within the UK however we have had no ongoing structured behavioural surveillance, although exposure categorisation of all HIV infection reports and AIDS case reports are obtained by CDSC. Some ad hoc surveys have been done by academic departments, health promotion units and others involved in the primary and secondary prevention of HIV.

Sampling methods and the geographic coverage has been rather haphazard. One of the more important surveys of gay men in London with a moderate sample size has been recently reported in the Communicable Disease and Public Health Journal and a copy of this is attached.

5. HIV/AIDS programme effectiveness monitored and evaluated by surveillance or surveys

Surveillance and survey results are fed into a national committee called The Expert Advisory Group on AIDS which scientific committee feeds directly into Department of Health policies. Currently the Department of Health is undertaking a compilation of an HIV/AIDS strategy and the initial conference to launch the process of pulling together a strategy was held in October 1998, (a report of this is attached with these documents). There is a commitment on the part of the Dept of Health for epidemiology and results of surveillance to play an important part in shaping the HIV/AIDS strategy.

6. CONCLUSION

Within the UK there is a well developed system of AIDS and HIV reporting and a family of unlinked anonymous sero-prevalence monitoring programmes which have enabled a thorough understanding of the HIV epidemic in the UK. Less well organised at this stage is behavioural monitoring. A well conducted national sexual attitudes and lifestyles survey was done in 1990 and a repeat is planned for next year (funding has just been agreed). Other ad hoc surveys of behavioural risks, especially in gay men, have been conducted by academic departments within London but this is not as well organised on a national scale.

HIV/AIDS surveillance systems in the United States

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5760I. Introduction

Historical perspective and public health importance

In 1981, soon after the first clusters of cases of *Pneumocystis carinii* pneumonia and Kaposi's sarcoma among gay men were reported¹, state and local health departments recognized that a new disease syndrome had made its appearance, and they began to collect case reports of the acquired immunodeficiency syndrome (AIDS)². These case reports were forwarded to the Centers for Disease Control (CDC) and formed the initial basis for AIDS surveillance years before the discovery of the causative agent, the human immunodeficiency virus (HIV), was identified. Cumulatively, as of June 1998, a total of 657,077 cases of AIDS among adults, adolescents, and children and 401,028 deaths due to AIDS had been reported to CDC³.

As the public health impact of AIDS in the United States was recognized, the data collection systems to monitor various aspects of the disease evolved rapidly in both number and complexity. However, because AIDS was incurable, nearly uniformly fatal, and largely transmitted sexually among gay/bisexual men or through sharing of injection equipment among substance abusers, the populations affected were concerned about stigmatization associated with AIDS diagnosis. Early in the epidemic, gay men, many of whom were well-educated and successful, organized themselves into politically active groups which were instrumental in bringing public and government attention to AIDS

and the concerns of the infected populations. Thus, surveillance for HIV and AIDS in the United States has developed in an environment of controversy between political activists concerned about protecting the individual rights of those infected and the public health community with responsibility to monitor the epidemic, allocate government resources and services, and prevent transmission. The surveillance systems existing today can be only be understood by examining this historical context^{4,5}.

Surveillance of HIV/AIDS and the populations at risk for HIV infection in the United States is accomplished through the following systems: HIV/AIDS reporting system (HARS); HIV seroprevalence studies; supplemental surveillance studies; national mortality statistics; and behavioral surveillance studies. These systems will be described in this report. In addition, there are other data collection systems related to service delivery, e.g., HIV counseling and testing system, Human Resources and Services Administration (HRSA) data collection systems for Medicaid/Medicare medical care services, etc., which will not be discussed.

II. HIV/AIDS surveillance

A. AIDS case surveillance

1. Organizational and legal structures for surveillance (Attachment A)

In the United States, the 50 state governments are the legal entities responsible for collection of surveillance data on individual cases of infectious diseases, including the acquired immunodeficiency syndrome (AIDS). Each state has passed legislation or written a rule to mandate data collection on individual cases of AIDS within its jurisdiction. On the basis of epidemiologic evidence that suggested an infectious etiology for AIDS, all states instituted reporting of AIDS cases during 1981-1982^{4,6} well before the causative virus was identified in 1983^{7,8}.

In contrast, surveillance and reporting of cases by state governments to the federal government (e.g., to the CDC) is voluntary. Although laws and rules for reporting requirements in each state may differ considerably, the Association of State and Territorial Health Officers (ASTHO) and the Council of State and Territorial Epidemiologists (CSTE) cooperate with CDC to set standards for consistency (e.g., standard case definitions), quality, and completeness of data⁹.

Privacy and security of HIV/AIDS data are critical to the success of national surveillance. There are stringent legal protections of privacy to government-held health information, and many states have imposed additional protections for HIV/AIDS data^{4,10-13}.

2. Reporting system (Attachment H)

CDC coordinates and funds HIV/AIDS surveillance activities through cooperative agreements with state and local departments¹⁴. There are 65 funded cooperative agreements [50 states, 6 large cities (Chicago, Houston, Los Angeles, New York City, Philadelphia, and San Francisco), the District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, the Republic of Palau, the Republic of the Marshall Islands, the Commonwealth of the Northern Mariana Islands, and the Federated States of Micronesia] which geographically cover the entire United States and its territories and possessions³. These areas use standardized data-collection methods, case definitions, data forms, and computer software developed by CDC.

State and local health departments collect information using active

and passive surveillance methods from multiple sources including: physician/provider reports, laboratory reports, medical record reviews, and patient/provider interviews (Figure 1). Information collected includes patient's and physician's names, date of diagnosis, demographic data (age, race/ethnicity, sex, date of birth, date of death), mode of exposure to HIV, clinical data (diagnoses of AIDS-indicator opportunistic infections), and laboratory criteria (HIV test results, CD4+ cell count, and viral load)¹⁴. The standardized case report forms have evolved over time; currently, adult and pediatric case report forms are available (Attachment C).

Data are entered into state/local databases on an ongoing basis and forwarded to CDC electronically each month. Data sent to CDC are encrypted without personal identifiers¹⁵. CDC can identify unique cases and regularly monitor the data for duplications using an alphanumeric code (soundex) based on the patient's surname and the state-assigned patient number.

In addition to legal protections of HIV/AIDS surveillance data mentioned earlier and later (see **HIV case reporting**), CDC has developed policies and procedures for the security and confidentiality protection of the data including: limitation of access to the electronic HIV/AIDS Reporting System (HARS) data bases; password protection of computer systems; reducing the number of access points to the HARS data through centralization; procedures of secure storage and destruction of hard copy documents containing identifiers; procedures for collecting and transferring data; procedures for analyzing and disseminating HARS data; and documentation of employee commitment to and training on data

security and confidentiality measures¹⁶. CDC regularly convenes meetings to update state/local health departments on these policies and procedures. In addition, on site visits are routinely done to review surveillance programs for adherence to these policies and procedures.

3. **AIDS case definitions (Attachment B)**

The surveillance case definitions for HIV and AIDS have evolved over time as our understanding of the clinical spectrum of HIV-related disease has changed¹⁴ (Table 1). Initially, the case definition was based on the diagnosis of specific opportunistic infections and malignancies resulting from cell-mediated immune deficiency⁶. In 1985, when the first HIV antibody tests became widely available, serologic evidence of HIV infection was incorporated into the case definition¹⁷. In 1986, a classification system for the clinical manifestations of HIV infection was introduced¹⁸. Most areas did not change AIDS case reporting based on this classification system; a few areas, however, did change surveillance for HIV cases by making a distinction between symptomatic and asymptomatic HIV cases (see **HIV case reporting**). In April 1987, a case definition for children <13 years of age was introduced¹⁹. Later in 1987, the clinical classification system was simplified and incorporated into the adult/adolescent case definition and other HIV-related conditions such as HIV encephalopathy and wasting syndrome were included²⁰. In 1993, the case definition was again expanded to include cases with a low CD4+ cell count (<200 cells/ μ L or <14%)²¹. The 1993 case definition also simplified the clinical classification system introduced in 1986 and incorporated it into the case definition. Several conditions for which

clinical management is complicated by HIV, e.g., pulmonary tuberculosis, recurrent pneumonia and cervical cancer, were also added to the list of AIDS indicator diseases. This is the case definition in current use²². In 1994, the pediatric case definition was revised to reflect the stage of disease for an HIV-infected child and to simplify and improve the accuracy of the classification system²³.

In order to accurately display trends, the AIDS surveillance data must be adjusted for the following: delays in reporting, persons reported without exposure risk, and changes in the case definition^{3,24}. Reporting delays (time between diagnosis of AIDS and report to CDC) may vary by exposure, geographic area, age and gender. About 80% of AIDS cases were reported within 1 year. Reporting delay adjustments are calculated by a maximum likelihood statistical procedure²⁵. “No identified risk” (NIR) cases are persons reported without an history of exposure to HIV through any of the routes listed on the case report form. Recently reported cases are more likely to be NIR cases because investigations to identify exposure routes may be incomplete. Therefore, recent AIDS incidence may underestimate some exposure categories without adjustment^{3,24,26}. Before 1993, AIDS incidence was based on the number of AIDS opportunistic illnesses (AIDS-OIs) diagnosed each year adjusted for delays in reporting and for redistribution of NIR cases. After 1993, the case definition included patients with severe immunosuppression (CD4+ cell counts < 200 cells μ /L) but who had not yet developed an AIDS-OI. This created a temporary distortion in the observed AIDS incidence. To examine trends over time, CDC developed